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American Heart Association testimony in strong SUPPORT of HB 467, HD1 "Relating to Health"

The American Heart Association strongly supports HB 467, HD1 "Relating to Health."

Congenital heart defects (CHD) are the most common birth defect in the U.S. and the leading killer of infants with birth defects. In the US, about 7,200 (or 18 per 10,000) babies born each year have one of seven critical congenital heart defects (CCHDs). An estimated 300 infants with an unrecognized CCHD are discharged each year from newborn nurseries in the United States. These babies are at risk for having serious problems within the first few days or weeks of life and often require emergency care.

Pulse oximetry newborn screening can identify some infants with a CCHD before they show any signs. Once identified, babies with a CCHD can be seen by cardiologists (heart doctors) and can receive specialized care and treatment that could prevent death or disability early in life. Treatment can include medications and surgery.

One of the best ways to detect CCHD is through a simple, noninvasive, inexpensive test, called **pulse oximetry**, or pulse ox. The pulse ox test consists of sensors placed on a baby's hand and/or foot to check blood oxygen levels. It is a simple bedside test to determine the amount of oxygen in a baby's blood and the baby's pulse rate. Low levels of oxygen in the blood can be a sign of a CCHD. The test is done using a machine called a pulse oximeter, with sensors placed on the baby's skin. The test is painless and takes only a few minutes.

If the baby's levels are too low, additional tests may be conducted. New research suggests wider use of pulse ox screening would help identify more than 90 percent of heart defects, with costs of the testing estimated at below \$4 per baby.

In September 2011, U.S. Secretary of Health and Human Services Kathleen Sebelius suggested that critical congenital heart defects screening be added to the "Recommended Uniform Screening Panel" for newborns before they are released from a hospital or birthing facility. To achieve this goal efforts are underway across the country to enact pulse ox screening policies that will allow babies with heart defects to live longer and fuller lives. At the time of this hearing, at least 36 states have passed legislation requiring pulse ox screening for all newborns. Others are expected to follow suit this year. Hawaii remains in the minority of those that currently don't require the screening.

HB 467, HD1 would help to insure that all Hawaii families are provided with the most recent standard of care-based health screenings for their newborns. The AHA urges Hawaii legislators support HB 467, HD1.

Respectfully submitted, Weismon

Donald B. Weisman

Hawaii Government Relations Director





Friday – February 27, 2015; 11:00 am Conference Room 308

HOUSE COMMITTEE ON FINANCE

Representative Sylvia Luke, Chair

Representative Scott Nishimoto, Vice Chair

From: Charles Neal, Jr., MD, PhD

Chief, Neonatology Department

Re: HB 467, HD1 Relating to Health

Testimony In Support

My name is Dr. Charles Neal, Jr., MD, PhD and I am the chief of the Neonatology Department of Kapi`olani Medical Center for Women & Children (Kapi`olani). Kapiʻolani Medical Center is the state's only maternity, newborn and pediatric specialty hospital. It is also a tertiary care, medical teaching and research facility. Specialty services for patients throughout Hawaiʻi and the Pacific Region include intensive care for infants and children, 24-hour emergency pediatric care, air transport, maternal-fetal medicine and high-risk perinatal care. The not-for-profit hospital offers several community programs and services, such as the Kapiʻolani Child Protection Center and the Sex Abuse Treatment Center. Additionally, Kapiʻolani's Women's Center is ranked among the top in the nation. Kapiʻolani Medical Center is an affiliate of Hawaiʻi Pacific Health, the state's largest health care provider.

I am writing in support of HD 467, HD1. This measure requires that birthing facilities perform a critical congenital heart defect screening using a pulse oximetry on every newborn in its care prior to discharge. The pulse oximetry is a non-invasive test that is an effective means of detecting critical, life-threatening congenital heart defects which may otherwise go undetected by current screening methods.

Kapi'olani Medical Center for Women & Children (Kapi'olani) has long followed the Academy of Pediatrics (AAP) guidelines which recognizes the importance of screening for congenital heart defects. We have established and apply pulse oximetry screening as the standard of care for all newborns to screen for congenital heart disease.

Thank you for the opportunity to provide this testimony.

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Testimony in SUPPORT of HB 467, HD 1 RELATING TO HEALTH

REPRESENTATIVE SYLVIA LUKE, CHAIR HOUSE COMMITTEE ON FINANCE

Hearing Date: February 27, 2015 Room Number: 308

- 1 **Fiscal Implications:** None. The added data collection, analysis, and dissemination activities
- 2 will be absorbed by the current Newborn Metabolic Screening Program staff and resources.
- 3 **Department Testimony:** The Department of Health supports HB467, HD1 to mandate birthing
- 4 facilities to do newborn screening for Critical Congenital Heart Defects (CCHD) using pulse
- 5 oximetry or another method recommended by the American Academy of Pediatrics, and to
- 6 provide newborn CCHD screening data to the Department of Health for quality assurance and
- 7 improvement activities.

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Data collection and information dissemination for quality improvement is needed. The algorithm and methodology for CCHD screening is not evidence-based but rather the best guess of a group of experts. Therefore, data need to be collected from real time screening of newborns with the outcomes to support and/or refine the methodology. This quality improvement activity is a required process especially in a state with a low birth rate like Hawaii and will allow Hawaii to participate in the national effort to refine and improve the methodology for CCHD screening.

Data are also needed to help birthing facilities recognize potential problems with their CCHD

screening that may cause inaccurate results.

The national incidence of CCHD is 2/1000 births. National and local pediatric cardiologists report that about 50% of the cases are detected prenatally. Some cases will have symptoms at birth. Best estimates are that about 1/2000 newborns with CCHD are asymptomatic and may be detected using pulse oximetry screening. With Hawaii's birth rate, screening could detect approximately 10 asymptomatic newborns with CCHD per year.

Thank you for the opportunity to testify on this measure.